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Home Ventilation in Northern Ireland

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SUMMARY

Thirteen patients were identified as receiving assisted ventilation at home in Northern Ireland in 1994. Two patients have since died. An increasing number of patients are starting home ventilation,, especially by nasal mask. Recognition of the needs of these patients and provision of care require further consideration.

INTRODUCTION

Long-term home mechanical ventilation was introduced over 50 years ago with the iron lung'. This was a life-saving treatment during poliomyelitis epidemics and provided ventilatory support by means of a negative pressure cuirass. In recent years there have been considerable advances in the development of portable ventilators to deliver intermittent positive pressure ventilation, especially by non-invasive means such as nasal mask. Patients with ventilatory failure from various causes such as central hypoventilation, muscular dystrophies and scoliosis, may benefit greatly from assisted ventilation at home. It is therefore important to develop a service for provision of home ventilation in Northern Ireland. The aim of this study was to identify the patients currently receiving assisted ventilation at home in Northern Ireland and to make an assessment of their needs and quality of life.

METHODS

As there is no central unit in Northern Ireland for initiating home ventilation, an attempt was made to identify patients by contacting consultants in the Belfast area and large district general hospitals who were most likely to care for patients requiring assisted ventilation at home ie. respiratory physicians, anaesthetists and neurologists. Some names were also obtained from the distributor of the NIPPY ventilator which is a portable ventilator for intermittent positive pressure ventilation (Medical Therapeutics Ltd. for Thomas Respiratory Systems, London). Case records were then checked to obtain information on the reason for ventilation and the type of ventilation system used. Only patients receiving intermittent positive pressure ventilation were selected; those patients receiving continuous positive pressure ventilation, referred to as CPAP, used to treat obstructive sleep apnoea, were excluded. There were no patients using negative pressure support systems. A total of 13 patients were identified during 1994. A questionnaire was sent to each patient to obtain information regarding ventilator use and quality of life. There were 12 questions regarding the practical use of the ventilator; space was left for further comments. Patients were asked to score quality of life on a visual analogue scale (1 to 7) and were asked specifically about their level of activity.

RESULTS

Details of the 13 patients are shown in the Table. All patients were initiated on the current mode of ventilation except patient 7 who initially used a nasal mask, but this became ineffective and he had a tracheostomy 2 years later. All but three patients had ventilation initiated in Northern Ireland. Aftercare, including maintenance of the ventilator, is varied and provided by the initiating

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TABLE

Demographic details of patients using home ventilation including the mode of delivery of ventilation, the date of starting long term ventilation and the site of initiation of ventilation.

Patient	*Age (years)*	*Sex*	*Diagnosis*	*Mode**	*Start date*	*Site***
1	37	F	Old poliomyelitis	T	Dec 1980	RICU
2	50	M	Acid maltase deficiency	T	June 1983	RICU
3	22	F	Minicore myopathy	T	Aug 1986	RBHSC
4	52	F	Mitochondrial myopathy	T	Oct 1987	RICU
5	19	M	Minicore myopathy	N	July 1990	RBHSC
6	13	M	Congenital muscular dystrophy	N	May 1991	RBHSC
7	40	M	Myotonic dystrophy	T	Nov 1991	Papworth
8	26	M	Central hypoventilation	T	Jan 1992	Papworth
9	39	M	Congenital kyphoscoliosis	N	Mar 1992	Papworth
10	40	F	Congenital kyphoscoliosis	T	May 1993	BCH ICU
11	32	F	Klippel-Feil syndrome	N	Sept 1993	BCH Resp.
12	33	F	Congenital kyphoscoliosis	T	Oct 1993	BCH ICU
13	67	M	Old thoracoplasty	N	Aug 1994	BCH Resp.

*T tracheostomy; N nasal mask.

**RICU Royal Victoria Hospital Intensive Care Unit, Belfast.

RBHSC Royal Belfast Hospital for Sick Children Intensive Care Unit, Belfast.

Papworth Respiratory Support Centre, Papworth Hospital, Cambridge.

BCH ICU Belfast City Hospital Intensive Care Unit.

BCH Resp. Belfast City Hospital Department of Respiratory Medicine.

units, the patient's local hospital and Medical Therapeutics Ltd. Questionnaires were received from all 13 patients. In response to practical questions, nine patients used the ventilator at night only, and three for part of the day as well as at night. One patient used the ventilator continuously. All patients found the ventilator easy to use and had someone at home to help. All patients had a telephone at home. Of 13 patients, six reported that the ventilator broke down on at least one occasion. This only occurred with patients who had been using the ventilator for more than two years. The machine was repaired within 24 hours in all cases, except for one patient who required hospital admission for several days until the repairs were done. Of 13 patients, eight felt that they could get advice 24 hours a day. One patient, who did not feel advice was readily available, suggested a 24 hour 'helpline' . Particular problems highlighted by patients included:

1. Nasal discomfort due to the mask.
2. Lack of regular servicing of the ventilator.
3. Difficulty in obtaining replacement parts eg. humidifier, tubing, filters.
4. Lack of battery power in the event of an electricity power failure.

Quality of life was measured on a scale of 1-7, with 1 = poor and 7 = excellent. Two patients felt that this was poor (score 1-2), seven patients felt this was reasonable (score 3-S) and four patients felt they had a very good quality of life (score 6-7). The lowest score (1) was given by patient 3 who used the ventilator continuously. The three

patients (7, 8 and 10) who used the ventilator for part of the day as well as at night all gave a score of 4. In terms of activity, 11/13 patients were up all day; one patient was up for half the day and another for short periods. No patient was confined to bed. The figure shows the types of activities patients were able to do. Of note, three patients were able to go to work. Two patients have since died during 1995: patient 11 died from worsening respiratory failure and patient 13 from a combination of renal failure, cardiac failure and respiratory failure.

DISCUSSION

Home mechanical ventilation is indicated for certain patients with chronic hypercapnic respiratory failure. It is particularly effective in those with neuromuscular diseases and chest-wall deformities.[1] Benefits can include an improvement in arterial blood gases, quality of sleep, exercise tolerance [2] and overall prognosis.[3] Home ventilation may be used in patients with chronic obstructive lung disease but the long term benefit is inconclusive at present.[4] Patients currently receiving home ventilation in Northern Ireland have neuromuscular diseases which are only slowly or non-progressive, chest wall deformities or central hypoventilation. There has been an exponential increase in patient numbers over the past 15 years, with 9 of the 13 patients having started home ventilation since 1990. Also, two-thirds of these patients were initially treated using a nasal mask. The increase in numbers probably reflects the advances in development of portable ventilators and the nasal mask for non-invasive delivery of ventilation. However, we have no record of patients who may have been using assisted ventilation at home but died prior to the start of this study. It is also important to note that, because of the lack of a central register, we may not have included all patients receiving home ventilation. Problems highlighted in the study included the lack of advice 24 hours per day, lack of regular servicing for some of the ventilators, and difficulty in obtaining disposable items such as tubing.

Use of home ventilation should be to improve quality of life as well as possibly prolonging life.[5] Quality of life was assessed in this study using a short unvalidated questionnaire. The results are not of any statistical significance, but give an overall impression of the quality of life for these patients as well as an assessment of their activity. A prospective study using a standardised questionnaire would be required to look at the effect of home ventilation on quality of life. The patients in this study are relatively young (mean

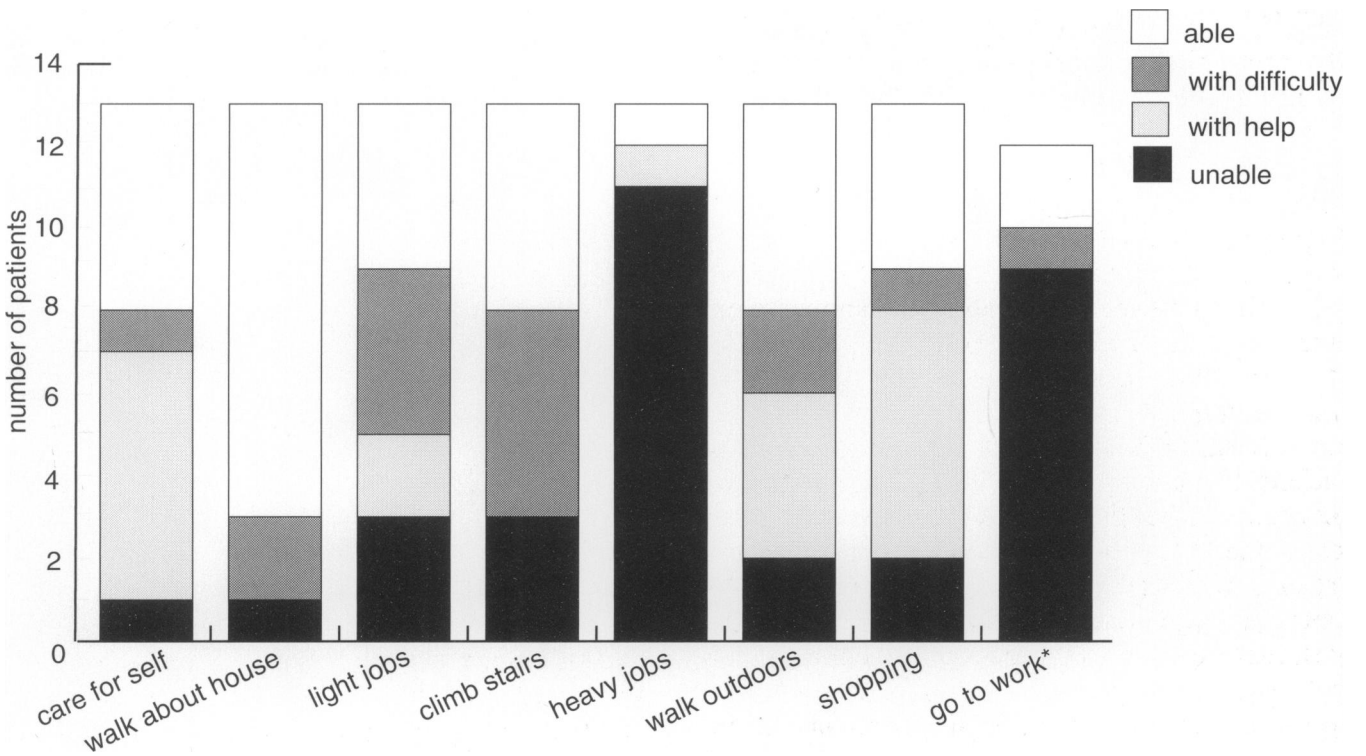

Fig Graph showing the ability of patients to perform certain tasks. *Patient 6 was excluded because of age (13 years).

age 36.2 years, range 13-67 years). Only 2 out of 13 patients felt that their quality of life was poor. Most were able to walk about the house and do light jobs; three patients even went out to work. An issue which is not addressed directly in this study is that of funding. With the lack of a central unit for commencing ventilation, there is no central funding mechanism. At present some ventilators are purchased with NHS funds, others are rented from Medical Therapeutics Ltd. Some funding is provided from the site of initiation of ventilation and some from the health board in the area where the patient resides. This issue requires further discussion and development of a comprehensive policy.

At present the number of patients in Northern Ireland receiving home ventilation is small but the number is steadily growing. In France, which has a well developed home care service, there are more than 5,000 people receiving home mechanical ventilation.[4,6] In the United Kingdom the number of patients requiring assisted ventilation at home is not known, but is currently estimated at around 2-3 per 100,000 population and expected to increase. The British Thoracic Society is currently setting up a register of patients receiving home ventilation in order to assess patient requirements nationally. In Northern Ireland, with a population of around 1.6 million, it may be conservatively estimated that around 40 patients require home ventilation. Options for managing these patients need to be considered, including the development of a specialist unit, either independently or within an existing department. The service provided should include assessment of patients with chronic respiratory failure and initiation of the appropriate mode of ventilation. There should also be adequate education and support for the patient and carers, including provision of a regular maintenance service for equipment and immediate advice should problems arise.

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